

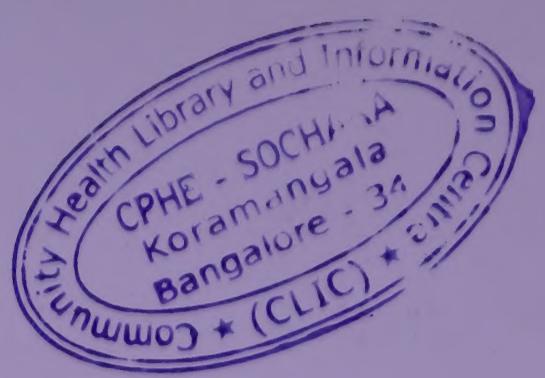


Definition of terms used in limitation of treatment and providing palliative care at end of life



INDIAN COUNCIL OF MEDICAL RESEARCH
2018





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DEFINITION OF TERMS USED IN LIMITATION OF TREATMENT AND PROVIDING PALLIATIVE CARE AT END OF LIFE



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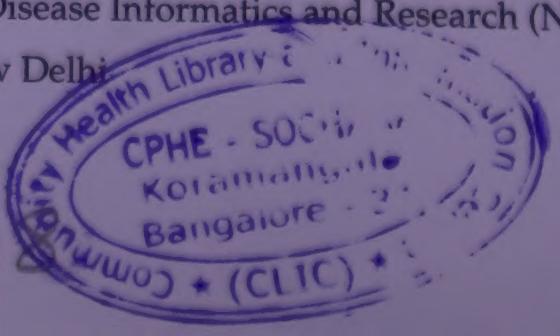


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Foreword

I am very glad that ICMR has formulated a document '**Definitions of terms used in limitation of treatment and providing palliative care at end of life**'. End-of-Life (EOL) care presents many challenges for clinicians as well as for patients and their families. The challenges faced by the terminally ill patients are substantial and potentially overwhelming; physical pain, depression and a variety of intense emotions, the loss of dignity, hopelessness and apparently tiresome tasks that need to be addressed at the end of life. An understanding of the dying patient's experience should help clinicians improve care for them.

One fundamental barrier to proper end-of-life care in India is the lack of clarity on several terms that are often mistaken. There has been a considerable evolution of terminology pertaining to this area of healthcare over the past three decades, which had raised the need of updating of the terms. There was an urgent need to bring the terminology to current world wide consensus definitions in order to overcome the prevailing confusion regarding understanding of the terms used in end of life care, which in turn results in havoc in clinical practice and in ambiguity in potential legislation.

The document discusses controversies on withholding or withdrawing life-sustaining treatment and how it is ethically and legally different from euthanasia as the latter is direct intentional killing of a person as part of the medical care being offered. It also explains active shortening of dying process, physician assisted suicide, surrogate and various other terms.

I hope this document will be helpful to clinicians as well as for patients and their families in better understanding of definition of terms pertaining to EOL care. I look forward to this document being widely referred to and followed by all the hospitals and medical centres all over the country for the better mitigation of suffering of terminally ill patients. With improved understanding of the matter over time, the document will be revisited and updated periodically.

(Soumya Swaminathan)

PREFACE

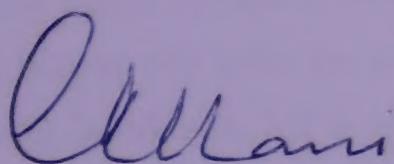
Currently, India has a huge opportunity to remove a major chunk of health-related suffering by providing ethical and legal guidelines covering end-of life-care (EOLC). The quality of EOLC in India has been rated to be among the worst 15 by the 'quality of death index' for 80 countries published recently by the Economic Intelligence Unit (2015) (1). Experts in the fields of Medicine and Bioethics have been concerned about the slow progress in improving EOLC in the country.

We believe, much of the delay in formulating EOLC guidelines have been due to misinterpretation of terms around appropriate treatment limitations. In the meanwhile, throughout the developed world, withdrawal and withholding of inappropriate medical interventions have become much easier through clarity in the ethical position of such decisions supported by progressive and pragmatic legislation. There is ambiguity in terms around limitation of life sustaining treatment. Previous law commission reports and Supreme Court judgements were unable to provide legal clarity. Aruna Shanbaug Case (2011) brought to the forefront the concerns and the issues related to EOLC since the globally accepted definitions of terms could not be directly applied in the Indian context (2). Following this case the term Passive euthanasia became legal but erroneous interpretation of the word has caused confusion and problems in social acceptability of the term (3). Moreover, lengthy procedural requirements in the real world has complicated the issue. In addition, Living Will has not been allowed by the Law Commission and the proposed draft bill on "medical treatment of terminally ill patients (protection of patients and medical practitioners)" by the Ministry of Health and Family Welfare. The issue is being heard by a Constitutional Bench of the Supreme Court in the Public Interest Litigation "*Common cause vs The Union of India*".

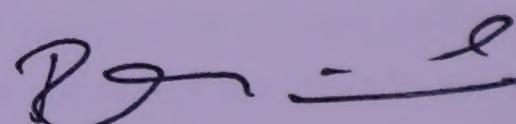
Respect for a person's Autonomy and privacy has been universally accepted. However, these rights need to be strengthened in Indian Law in the context of End of life care. The Right to Privacy as a fundamental right declared by a recent Supreme Court judgment (2017) is also expected to impact the legal position on Living Will. In the US, DNR was validated by Law in 1988, and further by the "Patient self-determination Act" and provisions for Advance Directives in 1991 (4). Recently, a poignant image was published in the New England Journal of Medicine (November 30, 2017): A 70-year-old with multiple co morbidities was brought comatose to the Emergency Room. He had the message "Do Not Resuscitate" (DNR) tattooed across his chest that

the doctors felt obliged to follow for ethical considerations (5). The issue brings into focus the enormity of moral distress possible when there is no mechanism to protect patient's right of choice when decision-making capacity is lost. Mention is made of the frequency of DNR in a cohort of patient deaths in an international publication from India. While DNR decisions are common place in most developed countries, the Indian study reported a DNR decision only in 3.5% of a cohort of 88 deaths due to the lack of legal clarity (6). Therefore, in India, in the absence of such settled laws, for resolving pending issues around EOLC, precise and updated definition of the terms is an essential prerequisite.

Indian Council of Medical Research has provided a unique opportunity, through the commissioning of an expert panel, to define the terms employed in EOLC. The expert group included a multi professional panel from the fields of Palliative Care, Critical care, Pulmonology, Neurology, Disease Informatics and Research, Basic Sciences, Ethics and Law. This was for the first time that in India we have a task force with a composition that acknowledges the overlap of multiple domains in the field of EOLC. The panel of experts has responded with a document that is carefully put together. We trust this will be a definitive step forward in improving EOLC and Palliative care for Indian patients.



Dr Raj Kumar Mani
GROUP CEO (Medical Services) &
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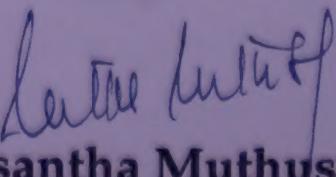
Dr M.R. Rajagopal
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MESSAGE

The Indian Council of Medical Research has been bringing out guidelines and guidance documents on various contemporary issues relevant to medical research and clinical practice over the last few decades. Since early 2000, documents have been prepared related to ethical guidelines, assisted reproductive technologies, organ transplantation, nutrition and disease related publications to help the researchers and the practitioners in the country. The latest effort in this regard is this consultative document to bring out clarity related to different terminologies pertaining to End of Life Care (EOLC) in terminally ill patients so that appropriate health care decisions can be arrived at by the public, physicians, judiciary and the policy makers without any ambiguity in this country.

The bioethical issues related to the management of terminally ill and those facing end of life options have been mind boggling to all the stakeholders handling these situations – individuals themselves, their family members, health care providers, socially aware citizens, judiciary and policy makers with their respective perspectives. The application of ethical principles of autonomy, non- maleficence, beneficence and justice along with preservation of the individual's dignity and rights for arriving at appropriate decisions related to withdrawal and withholding treatment, prioritisation of the available limited health care provisions, advance directives or living will and permitting passive euthanasia have been a moral dilemma all over the world. In the absence of clear cut guidance in this regard, we are facing a lot of ethical and legal debates in India with respect to EOLC.

The correct consensus definition of terms related to EOLC has not been clear till now due to different interpretations of these terminologies nationally and internationally resulting in inappropriate decision making at different levels – medical, social, legal, judicial etc. hence there was an urgent need to create a consensus document which will be acceptable to all stakeholders in India. This timely initiative to bring out this document entitled, "Definition of terms used in palliative care at end of life" involving those caring for terminally ill patients and end of life care issues and taking it through a series of consultations is a commendable effort. This will be a landmark document in this country and will benefit one and all.



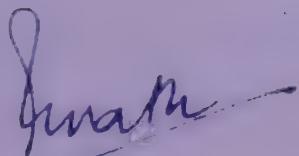
Dr Vasantha Muthuswamy
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ACKNOWLEDGEMENT

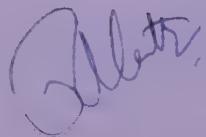
We acknowledge the encouragement and patronage of Dr Soumya Swaminathan, DG ICMR and Secretary DHR, for commissioning an expert group to finalize definitions of terms pertaining to End of Life Care.

The consistent efforts and contribution of Dr M.R. Rajagopal and Dr Raj Kumar Mani who led the discussions in the group towards the preparation and finalization of the definitions is gratefully acknowledged. We also thank Dr Naveen S Salins, Tata Memorial Hospital for all his kind inputs in putting this report together. Special thanks are due to all the members of the expert group who drafted the initial write up as well as stakeholders from all parts of the country who provided their valuable comments and suggestions when the document was posted on website for public consultation. We also thank Dr Rajib Kishore Hazam and Dr Kalyani Thakur for coordinating this initiative at ICMR-NCDIR, Bengaluru.

End of life care encompasses needs for those patients with a terminal illness or terminal stage that has become too advanced, progressive and incurable. This document has defined the terminologies related to EOLC so as to make a beginning to understand the scope and guidance for end of life care in this country.



Dr Prashant Mathur
Director
NCDIR, Bangalore



Dr Roli Mathur
Scientist E & Head ICMR Bioethics Unit
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EXECUTIVE SUMMARY

This consensus document was prepared in order to standardize, update and remove ambiguities in the definitions of terms relating to end of life care (EOLC). This is required to facilitate dialogue, data collection and research, towards informing the development of bioethics and law relating to these areas.

Definitions:

Terminal illness: An irreversible or incurable disease condition from which death is expected in the foreseeable future.

Actively Dying: The hours or days preceding imminent death during which time the patient's physiological functions wane.

Life sustaining treatment: Life sustaining treatment comprises of any medical treatment that artificially supports or replaces, a bodily function essential to the life of the person.

Potentially inappropriate treatment: It connotes interventions aimed at cure that carry far greater possibilities of harm than reasonable possibilities of benefit.

Cardiopulmonary Resuscitation (CPR): It is an emergency medical procedure that combines chest compression often with artificial ventilation.

Do not attempt Resuscitation (DNR): A decision not to initiate or perform CPR on the background of terminal illness in accordance with prior expressed wishes of the patient or surrogate.

Withholding of life sustaining treatment: A decision made not to initiate or escalate a life-sustaining treatment in terminal illness in accordance with expressed wishes of the patient or surrogate.

Withdrawal of life sustaining treatment: A decision made to cease or remove a life-sustaining intervention in terminal illness in accordance with expressed wishes of the patient or surrogate.

Euthanasia: Euthanasia is the intentional act of killing a terminally ill patient on

voluntary request, by the direct intervention of a doctor for the purpose of the good of the patient.

Active shortening of life process: An active intentional act to hasten death or shorten the life of a dying patient with terminal illness.

Physician assisted suicide: An intentional act by the physician, on voluntary request of a dying patient with terminal illness, providing the means or methods with which to help a person to end his/her life.

Palliative Care: Palliative care is a holistic approach to treatment that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.

End of life care: An approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life.

Palliative sedation: Palliative sedation is the administration of sedative substances at the minimal dosages necessary intentionally to lower the consciousness level definitely or temporarily in a terminally ill patient.

Double Effect: A principle that distinguishes the effects that are intended, from those that are unintended but may be adverse though foreseeable.

Death: Irreversible cessation of the heart and circulatory function, or neurological function of the brain including the brain stem.

Best Interests: A concept that requires physicians to ensure potential benefits to outweigh harms before undertaking medical interventions.

Healthcare Decision making capacity: The capacity of a patient to make an independent, informed decision.

Shared decision making: A dynamic process with responsibility for decisions about the medical care of a patient being shared between the health care team and the patient or surrogates.

Advance Directives: A statement made by a person with decision-making capacity

stating his/her wishes regarding how to be treated or not treated at a stage when s/he loses such capacity.

Surrogate: Surrogate is a person or persons other than the healthcare providers who is/are accepted as the representatives of the patient's best interests, who will make decisions on behalf of the patient when the patient loses decision-making capacity.

Autonomy: It is the right of an individual to make a free and informed decision.

Beneficence: A principle that makes it obligatory on the part of physicians to act in the best interests of patients.

Non-maleficence: A principle that directs physicians to first of all not do harm.

Justice: In the context of medical care requires that all people be treated without prejudice and that healthcare resources be used equitably.

INTRODUCTION

In the words of Lisa J Schultz "If the push towards life sustaining technology were balanced with options for comfort care, more people would have the chance to transition to death with dignity and grace." Such a trend of pragmatism, driven by ethical considerations and humanistic values, has been palpably lacking in India. Indian hospitals in general lack policies on limitation of inappropriate life sustaining interventions at the end of life. In contrast in the USA and Europe, such treatment limitations permit natural death in upto 90% of cases. (7, 8). Only a few centres in India report withdrawal of inappropriate life-sustaining interventions, where it preceded death in 22% - 49% of deaths (9-11). Anticipatory directives and advance care planning are almost non-existent and patients are seldom referred to palliative care for symptom management and end of life care (12). Family and caregivers of the deceased patients often feel that the patients at the end of life have poorly controlled symptoms and distress (13). Health related communication is incompletely delivered as most hospitals do not have trained healthcare providers equipped to provide end of life care (14). Patients are often burdened with impersonal and unwanted health technology at the end of life with humane and comforting touch usually lost in the bargain (10).

The duty of the health care provider is to mitigate suffering (15). It is "to cure sometimes, to relieve often and to comfort always" (16). There exists no exception to this principle, whether or not there is a medical consensus, when the disease is incurable and the death is imminent. Death is to be recognized as a natural culmination of life (17). Care providers have the primary duty to improve quality of life all through life which includes the dying phase. In the latter situation, curative intent must give way to a focus on improving the quality of life of the patient (18). Indiscriminate and aggressive medical interventions in such situations violate the individual's right to live and die with dignity (19). Medical procedures must thus inevitably be limited, at a point judged by health care providers, that continuation of treatment would cause considerable harm compared to benefits. Treatment limitation is an integral part of the shift of the goal of care from a cure-directed approach to palliative care and end of life care (20).

End of life care is a person centred, personalized perception of "Good Death", which encompasses all aspects of comprehensive care of an individual who is approaching

his or her end of life (21). It is applicable to any person, any place and any illness. It involves relief of physical, psychological, social, spiritual and existential symptoms (22). It enables patients to die at the preferred place of choice and receive appropriate care by a trained health care provider. It aims to provide universal access to standard palliative care at the end of life and believes that every individual should have a right to a good, peaceful, comfortable and dignified death (23).

There has been a considerable evolution of terminology pertaining to this area of healthcare over the past three decades. In India the paradigm has remained rooted in curative treatment in all phases of life. The shift from care to cure has not been integrated into everyday practice. Quality of death as reflected in peace, dignity and family presence at the time of death is seriously compromised when patients die in ICUs or hospitals, as most prefer to die distress-free at home. Since this aspect of holistic healthcare is missing in our collective awareness, palliative care access in terms of infrastructure and expertise is limited. Understandably, corresponding evolution of bioethics has also been hampered. Consequently, bioethical concepts remain outdated and insufficient to resolve dilemmas continually generated by new developments in medicine. Moreover, the ethical principles governing the deployment and forgoing of life support technologies have largely remained outside public and professional focus. One fundamental barrier to professional and public discourse on these issues in India is the lack of clarity on the spectrum of terms that are often mistaken for euthanasia. Although international consensus definitions exist in medical literature, they need to be interpreted and integrated into Indian healthcare and cultural awareness. Therefore, the terminology pertaining to these fields have so far been alien to our common understanding. This scenario needs to be urgently addressed in order to bring our principles and practice up-to-date. This consensus document on terminology is prepared under the aegis of the Indian Council of Medical Research (ICMR) towards realizing this goal. It is of crucial importance to develop India-specific ethical and legal framework for end of life decision-making in clinical practice.

The following are the definitions of common terms used in end of life care and palliative care agreed upon by this expert group appointed by ICMR. These are based on a review of existing international documents and national consensus on the matter.

Methodology

Using Nominal Group (24) and Delphi method (25) the consensus statement on

definition of terms used in limitation of treatment and providing palliative care at end of life was created. Nominal group method was conducted on 29th April 2017 at Mathura, India in which an expert group comprising of critical care physicians, palliative care physicians, neurologists, physicians, ethicists, solicitors and members from the lay public participated. The expert group discussed the contentious statements/items in the draft document until a consensus was achieved and a final set of draft definitions were created. Post nominal group consensus meeting, a detailed draft of the definition of terms document emerged through a Delphi process. This draft document was placed in the ICMR website inviting expert and public comments. The comments received were incorporated and document was revised and recirculated among the experts until final consensus was achieved.

FINALISED DEFINITIONS

Glossary of Definitions

1.	Terminal illness	Terminal illness is one from which recovery cannot be expected with the available treatment and death is considered to be unavoidable in the foreseeable future (26). OR An incurable and irreversible condition caused by injury, disease, or illness that would cause death within a reasonable period of time in accordance with accepted medical standards, and where the application of life-sustaining treatment would serve only to prolong the process of dying (27).
2.	Actively dying	The hours or days preceding imminent death during which time the patient's physiological functions wane (27).
3.	Life sustaining treatment	Life sustaining treatment comprises of any medical treatment that artificially supports or replaces, a body function essential to the life of the person. It includes cardiopulmonary resuscitation (CPR), endotracheal intubation, mechanical ventilation, vasopressor therapy, parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, and intravenous fluids (28).
4.	Potentially inappropriate treatment (disproportionate treatment, non-beneficial treatment, inadvisable treatment)	It connotes interventions aimed at cure that carry greater possibilities of harm than reasonable possibilities of benefit. There is no general consensus about the use of the related term futility and use of this term should be avoided (29).
5.	Cardiopulmonary resuscitation (CPR)	It is an emergency medical procedure that combines chest compression often with artificial ventilation, <i>in an effort to manually preserve intact brain</i>

function until further measures are taken to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest (30).

6. Do not attempt cardiopulmonary resuscitation (DNR or DNAR) Not for resuscitation (NFR)

A decision not to initiate or perform the CPR, on the background of terminal illness where the patient's chances of surviving in the event that he/she needs CPR are extremely low and the patient fully aware of his/her terminal illness or if the patient is incompetent, a surrogate on behalf of the patient decides not to undergo CPR (31).

7. Withholding life sustaining treatment

On a background of terminal illness, a decision made not to initiate or escalate a life-sustaining treatment, where the patient's chances of survival after initiation or escalation of life sustaining treatment, is poor, with the burden outweighing the possible benefit, and the fully informed patient or if the patient is incompetent, a surrogate on behalf of the patient, chooses not to initiate or escalate the life-sustaining treatment (32).

8. Withdrawing life sustaining treatment

On a background of terminal illness, a decision made to cease or remove a life-sustaining intervention presently provided, where patient's chances of survival with continued life sustaining treatment is poor with the burden outweighing the possible benefit and the fully informed patient or if the patient is incompetent, a surrogate on behalf of the patient, chooses to cease the life-sustaining treatment (32).

9. Euthanasia

Euthanasia is the intentional act of killing a dying patient with terminal illness by the direct intervention of a doctor, for the purpose of good of the patient. However, allowing natural death, withholding and withdrawing of life sustaining treatment to limit harm and suffering in a dying

		<p>patient should not be construed as Euthanasia (33).</p> <p>The term passive euthanasia is an obsolete terminology and should be avoided as euthanasia cannot be passive and withholding or withdrawing a potentially inappropriate treatment in a patient dying with a terminal illness that only prolongs the dying process, cannot be construed as an intention to kill.</p>
10.	Active shortening of dying process	<p>An active act intended to hasten death or shorten the life of a dying patient with terminal illness. However, allowing natural death, withholding and withdrawing of life support to limit harm and suffering in a dying patient should not be construed as active shortening of life (8).</p>
11.	Physician assisted suicide	<p>An intentional act by the physician, on voluntary request of a dying patient with terminal illness, providing the means or methods with an intention to help a person to end his/her life (34).</p>
12.	Palliative Care	<p>According to the WHO, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (35).</p>
13.	End of Life Care	<p>An approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life (36).</p>

14.	Palliative Sedation	<p>Palliative sedation is the intentional administration of sedative substances at the minimal dosages necessary to lower the consciousness level definitely or temporarily of a person suffering from a terminal illness and having a short life expectancy (days to weeks) in order to obtain relief from one or several distressing symptoms refractory to standard treatment methods (37).</p> <p style="text-align: center;">OR</p> <p>Therapeutic (or palliative) sedation in the context of end of life care is the monitored use of appropriately titrated medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering due to distressing refractory symptoms in a manner that is ethically acceptable to the patient, family and health-care providers (38).</p>
15.	Double effect	<p>This principle distinguishes the effects that are intended, from those that are foreseeable though unintended. The principle justifies the appropriate use of palliative analgesia and sedation, specifically to relieve suffering, even at the remote risk of hastening death as a side effect, which is unintended (39).</p>
16.	Death	<p>Irreversible cessation of the heart and circulatory function, or neurological function of the brain including brain stem (40).</p> <p style="text-align: center;">OR</p> <p>“Deceased Person” means a person in whom permanent disappearance of all evidence of life occurs, by reason of brain-stem death or in a cardio-pulmonary sense, at any time after live birth has taken place (41).</p>

17.	Best interests	The best interest concept holds that the physicians and other healthcare providers must weigh the benefits and risks of treatments and select ones in which the benefits are maximized and the risks minimized for the patient. This is not based on value judgments but on objective criteria prescribed by professional and societal standards (42).
18.	Health care decision making capacity	Health care decision making capacity is the capacity of an individual to make an informed decision after fully understanding the nature of intervention, purpose of intervention, risks and benefits of intervention, risks of not carrying out the intervention and risks and benefits of alternate interventions (42).
19.	Shared decision-making	A dynamic process with responsibility for decisions about the medical care of a patient being shared between the health care team and the patient or the patient's surrogates (43).
20.	Advance directives	A statement made by a person with the decision-making capacity stating his/her wishes regarding how to be treated or not treated at a stage when s/he loses such capacity. Advance directives include living wills or health care proxies and become operational only after the person loses capacity (44).
21.	Surrogate	Surrogate is a person or persons other than the healthcare providers who is/are accepted as the representatives of the patient's best interests, who will make decisions on behalf of the patient when the patient loses his/her capacity to make health care decisions. It has to be a designated/nominated person by the patient, who may or may not be a family member. In absence of such designation or nomination, the next of kin of the patient will be considered as surrogates (44).

22.	Autonomy	<p>Autonomy is the right of an individual to make a free and informed decision. Autonomy in the context of medical practice, includes the patient's right to full information and to participate in medical decision-making. This includes the right to refuse interventions (45).</p> <p>The person's right to autonomously voice their end-of-life treatment choices has to be respected, considering the use of advance treatments and their prognosis. This right of autonomy has some limitations, and hence may face an ethical dilemma. Ethics require that patients do not receive end-of-life care which is inconsistent with their end-of-life care preferences.</p>
23.	Beneficence	<p>This principle makes it obligatory on the part of physicians to act in the best interests of patients (46).</p> <p>Physicians have to judge the end of life care situation and provide appropriate treatment prognosis so that patients can make an autonomous choice of treatment preferences or patients' family can make these choices for them and work towards act of beneficence for the patient. While carrying out this act of beneficence, the physician has to provide information about the treatment, especially in case of futile treatments so as to avoid any undue harm to the patient. The healthcare services should not only target lengthening the life of patients but also improve their quality of life.</p>
24.	Non-maleficence	<p>This principle directs physicians to first of all not do harm. The harm also includes harm to patients' whole person interests, expressed as values and wishes (47).</p>

25.	Justice	<p>In the context of medical care requires that all people be treated without prejudice and healthcare resources be used equitably (48). Rationing of care is present in the current healthcare system in most countries and can be justified if carried out ethically and equitably. There is a need for evaluating and assessing the medically advanced treatment so as to avoid any undue use of already limited resources. Considering the aspect of access of quality care to the people who need them most, rationing of care in futile situations is often justified.</p>
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EXPLANATORY NOTES

1. Terminal illness

According to the International Association of Hospice and Palliative Care, terminal illness is a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant conditions and aging. A person has an eventually fatal condition, if his/her death in the foreseeable future would not be a surprise. The terms eventually fatal or terminal condition are used interchangeably. In reference to the patient, language that refers to living with an eventually fatal or terminal condition is recommended (27).

According to the American Cancer Society, it is an irreversible condition that in the near future will result in death or a state of permanent unconsciousness from which he/she is unlikely to recover. In most states, a terminal illness is defined as one in which the patient will die "shortly" whether or not the medical treatment is given (49).

According to the Mosby's medical dictionary, terminal illness is an advanced stage of a disease with an unfavourable prognosis and no known cure.

Various authorities have quoted a specific

duration of 6 months or 12 months. However, there is no objective evidence to support time frames. Therefore, this document does not provide any specific time frames.

2. Actively dying

Actively dying has not been well defined in the literature. It is normally described in terms of the last hours or days of life, and presence of unique signs and symptoms preceding death. There is a paucity of literature on the signs of impending death. Further studies are needed to examine specific signs that may signal that the patient is actively dying and to allow clinicians to educate family members and make appropriate recommendations toward maximizing comfort and minimizing aggressive measures (27).

3. Life sustaining treatment

According to the British Medical Association, this refers to all treatments which has the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, left ventricular assisted devices, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis,

antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration (50).

4. Potentially inappropriate treatment

According to the official policy statement of the American Thoracic Society, the American Association for Critical Care Nurses, the American College of Chest Physicians, the European Society for Intensive Care Medicine, and the Society of Critical Care Medicine, the term “potentially inappropriate” should be used, rather than “futile,” to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. Clinicians should communicate and advocate for the treatment plan they believe is appropriate. Requests for potentially inappropriate treatments that remain intractable despite intensive communication and negotiation should be managed by a fair process of conflict resolution (51).

Justification: The committee recommends use of the term “potentially inappropriate” rather than “futile” to emphasize two important aspects of such judgments. First, the word “inappropriate” conveys more clearly than the word “futile” or “ineffective” that the assertion being made by clinicians depends both on technical medical expertise and a

value-laden claim, rather than strictly a technical judgment. Second, the word “potentially” signals that the judgments are preliminary, rather than final, and require review before being acted on. The ethical concerns that may be raised to justify the refusals include concerns that the treatment is highly unlikely to be successful, is extremely expensive, or is intended to achieve a goal of controversial value.

5. Cardiopulmonary resuscitation

According to the International Liaison Committee on Resuscitation, Cardiopulmonary resuscitation, commonly known as CPR, is an emergency procedure that combines chest compression often with artificial ventilation in an effort to manually preserve intact brain function until further measures are taken to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest. It is indicated in those who are unresponsive with no breathing or abnormal breathing, for example, agonal respirations (30).

6. Do not attempt resuscitation

According to the American Heart Association guidelines, a Do Not Attempt Resuscitation (DNAR) order is given by a licensed physician or alternative authority as per local regulation, and it must be

signed and dated to be valid. In many settings, "Allow Natural Death" (AND) is becoming a preferred term to replace DNAR, to emphasize that the order is to allow natural consequences of a disease or injury, and to emphasize ongoing end-of-life care. The DNAR order should explicitly describe the resuscitation interventions not to be performed in the event of a life-threatening emergency. In most cases, a DNAR order is preceded by a documented discussion with the patient, family, or surrogate decision maker addressing the patient's wishes about resuscitation interventions. In addition, some jurisdictions may require confirmation by a witness or a second treating physician (52).

7. Withholding life sustaining treatment.

According to the Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998 in the US, it is the decision to withhold medical treatment prospectively: that is, whether or not to commence treatment for an event/s yet to take place. This may involve a dimension of uncertainty, because there could be unknowns about the future clinical state of the patient, for example, when and if the patient will suffer a cardiac arrest, necessitating CPR (53).

8. Withdrawing life sustaining treatment

According to the Guardianship and

Administration Act 2000 and the Powers of Attorney Act 1998, in the US, the decision to withdraw a life-sustaining measure implies that a level of acceptance about the benefits of continuing the measures has been reached, both by the clinicians involved and the family. The decision signifies that a stage has been reached where the evidence points to the fact that the patient undeniably and irrefutably is receiving no benefit from the interventions proposing to be withdrawn. Arguably, the consent processes for withdrawing medical treatment may be less onerous than for withholding medical treatment, most likely because the patient's condition has stabilized to the extent that no further improvement is expected (53). The worldwide consensus is that both withdrawal and withholding are ethically acceptable in the context of EOLC, are similar and are to be considered together (54). They both flow from the same principle of reducing unwanted harms to a terminally ill patient. Physicians and family may experience more distress and dilemma with the withdrawal decision. Both are based on the premise that the dying process is attributable to the disease afflicting the patient and not to the acts of withholding or withdrawal as they both belong to the principle of "omitting to struggle" when harms outweigh benefits. In both cases the treatment shifts to comfort care in meticulous detail (55). If withdrawal were to be avoided at all

costs then the opportunity of a trial of curative interventions could be lost to some patients.

9. Euthanasia

Euthanasia is defined as direct intentional killing of a person as part of the medical care being offered. The withholding or withdrawing of artificial life support procedures for a terminally ill patient is not euthanasia. Withholding/ withdrawing life sustaining treatment taking into account the patient's benefits, wishes of the patient and family and when based upon the principle of the potential inappropriateness of treatment for a terminal patient, is legally acceptable and appropriate (33).

Passive euthanasia: Although the term passive euthanasia is used by some people to mean withholding or withdrawing life sustaining treatment, the term is not used in medically advanced countries when the subject is officially discussed. Notable examples include deciding to forego Life-Sustaining Treatment (A report on the ethical, medical, and legal issues in treatment decisions) published by the Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research of USA 1983, and the Report of the House of Lords Select Committee on Medical Ethics of UK 1994. The term is also not used in the professional guidelines on the

subject in various medically advanced countries (56).

Withholding or withdrawing life-sustaining treatment, if done under appropriate circumstances, is ethically and legally acceptable. This is ethically and legally different from euthanasia as the latter is direct intentional killing of a person as part of the medical care being offered. To use the term passive euthanasia to describe the appropriate withholding or withdrawal of life-sustaining treatment may give people the wrong impression that such a decision is ethically and legally similar to active euthanasia. Withholding or withdrawing life-sustaining treatment includes widely different situations, ranging from withholding cardiopulmonary resuscitation in a terminally ill malignancy patient, to withdrawing artificial nutrition in a patient in persistent vegetative state. The former is non-controversial but the latter can be controversial. If the term passive euthanasia is used, people may relate all discussions around withholding or withdrawing life-sustaining treatment to the controversial situations like the latter (57).

The term passive euthanasia may contain the meaning of an intention to kill. We support withholding or withdrawing futile treatment which only prolongs the dying process, but we do not support an intention to kill. Avoiding the misleading

term passive euthanasia but using the more neutral term withholding or withdrawing life-sustaining treatment would thus facilitate public discussion on the topic. This would also facilitate discussion with the patients and families in individual cases when such discussion is required (58).

10. Active shortening of life

According to the ethics in European intensive care units (ETHICUS) study, active shortening of the dying process was defined as a circumstance in which someone performed an act with the specific intent of shortening the dying process; these acts did not include withholding or withdrawing treatment although withholding or withdrawing could occur prior to shortening of dying process. Examples included an intentional overdose of narcotics, anaesthetics, or potassium chloride (8).

The term "shortening of the dying process" was used instead of active euthanasia because Dutch investigators insisted that the term "active euthanasia" could not include most ICU patients who could not request the action. Several other terms were considered, but shortening of the dying process was accepted by all investigators as it describes the intent, the action that occurs, and is a more neutral term that physicians might more readily record. In addition, as some investigators

might still be reluctant to admit to shortening of the dying process, another question was added to evaluate the highest possible incidence of actions that might be considered active euthanasia (although most of these actions were probably not active euthanasia). For each patient, physicians were asked whether any other action (not forgoing therapy) taken to relieve patient suffering may have contributed to the patient's death (59).

11. Physician assisted suicide

According to the Hastings Centre Bioethics briefing, Physician-assisted suicide refers to the practice where a physician provides a potentially lethal medication to a terminally ill, suffering patient at his request that he can take (or not) at a time of his own choosing to end his life. It is also called physician-assisted suicide, physician aid-in-dying, and patient administered hastened death (60).

12. Palliative Care

According to WHO, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (35).

Palliative care:

- 1) provides relief from pain and other distressing symptoms;
- 2) affirms life and regards dying as a normal process;
- 3) intends neither to hasten or postpone death;
- 4) integrates the psychological and spiritual aspects of patient care;
- 5) offers a support system to help patients live as actively as possible until death;
- 6) offers a support system to help the family cope during the patients illness and in their own bereavement;
- 7) uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- 8) will enhance quality of life, and may also positively influence the course of illness;
- 9) is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (35).

13. End of life care

According to the General Medical Council, UK, patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events. The term 'approaching the end of life' can also apply to extremely premature neonates whose prospects for survival are known to be very poor, and patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment and care may lead to their death (61-63).

Palliative care encompasses end of life care. Therefore, these terms are being increasingly used together as they both are essential components for the holistic care at the end of life. Guidelines on end of life care tell us that palliative care starts side by side with curative intent and carries on as an increasing component becoming the mainstay of treatment in end of life care. Treatment limitation does not indicate abandonment of patient but shift in the focus of care from cure to

comfort and improvement in quality of life (64).

14. Palliative Sedation

According to the position statement of American Association of hospice Palliative Medicine, palliative sedation (PS), as defined in this statement, is the intentional lowering of awareness towards, and including, unconsciousness for patients with severe and refractory symptoms (65).

Palliative sedation must satisfy the criteria of having a specific clinical indication, a target outcome, and a benefit/risk ratio that is acceptable to both the clinician and the patient or patient's surrogates. Palliative sedation is an intervention reserved for extreme situations. The use of palliative sedation should only be considered after all available expertise to manage the target symptom has been accessed. The level of sedation should be proportional to the patient's level of distress. As with all treatments, patients, when able, should participate in the decision to use palliative sedation. Treatment of other symptoms should be continued alongside palliative sedation, because sedation may decrease the patient's ability to communicate or display discomfort (37).

Palliative sedation raises ethical concerns when it significantly reduces patient

consciousness to the degree that the patient is unable to substantially interact with others, does not have the ability or opportunity to change his mind, and is unable to eat and drink (thus potentially shortening survival in particular circumstances). Palliative sedation is ethically defensible when used 1) after careful interdisciplinary evaluation and treatment of the patient, and 2) when palliative treatments that are not intended to affect consciousness have failed or, in the judgment of the clinician, are very likely to fail, 3) where its use is not expected to shorten the patient's time to death, and 4) only for the actual or expected duration of symptoms. Palliative sedation should not be considered irreversible in all circumstances. It may be appropriate, in some clinical situations when symptoms are deemed temporary, to decrease sedation after a predetermined time to assess efficacy, continued symptoms and need for ongoing sedation (38).

In clinical practice, palliative sedation usually does not alter the timing or mechanism of a patient's death, as refractory symptoms are most often associated with very advanced terminal illness. Practitioners who use palliative sedation should be clear in their intent is to palliate the symptoms and not to shorten survival. Because patients receiving palliative sedation are typically close to death, most patients will no longer have

desire to eat or drink. Artificial nutrition and hydration are not generally expected to benefit the patient receiving palliative sedation. However questions about the use of artificial nutrition and hydration should be addressed before palliative sedation is undertaken (66).

Sedation is used in palliative care in several settings: 1) transient sedation for noxious procedures; 2) sedation as part of burn care; 3) sedation used in end of life weaning from ventilator support; 4) sedation in the management of refractory symptoms at the end of life; 5) emergency sedation; 6) respite sedation; 7) sedation for psychological or existential suffering. However, sedation for psychological and existential suffering needs greater exposition and consensus before it is considered as grounds for practice of palliative sedation in the Indian setting.

15. Double effect

The essence of the doctrine of double effect is that an act performed with good intent can still be moral despite unforeseen unintended effects. In the context of end of life care, this can arise when four conditions are met (39):

- 1) Administering strong analgesics for relief of severe pain is not, in itself, immoral.
- 2) The intention is to relieve severe pain, and not to hasten the patient's

death.

- 3) The relief of severe pain is not achieved through causing the patient's death.
- 4) Proportionally, the need to relieve severe pain is such that it warrants accepting a remote possibility of shortening of life.

16. Death

According to the Academy of Medical Royal Colleges, Death is defined as the simultaneous and irreversible onset of apnoea and unconsciousness in the absence of the circulation (67). Full and extensive attempts at reversal of any of the contributing cause to the cardiorespiratory arrest have been made. Such factors, which include body temperature, endocrine, metabolic and biochemical abnormalities.

Moreover, death could also ensue due to an individual meeting the criteria for not attempting cardiopulmonary resuscitation or attempts at cardiopulmonary resuscitation have failed or treatment aimed at sustaining life has been withdrawn because it has been decided to be of no further benefit to the patient and not in his/her best interest to continue and/or is in respect of the patient's wishes via an advance decision to refuse treatment.

The individual should be observed by the person responsible for confirming death for a minimum of five minutes to establish that irreversible cardiorespiratory arrest has occurred. The absence of mechanical cardiac function is normally confirmed using a combination of the following: — absence of a central pulse on palpation and the absence of heart sounds on auscultation. These criteria will normally suffice in the primary care setting. However, their use can be supplemented in the hospital setting by one or more of the following: — asystole on a continuous ECG display, absence of pulsatile flow using direct intra-arterial pressure monitoring or absence of contractile activity using echocardiography.

Any spontaneous return of cardiac or respiratory activity during this period of observation should prompt a further five minutes' observation from the next point of cardiorespiratory arrest. After five minutes of continued cardiorespiratory arrest the absence of the pupillary responses to light, of the corneal reflexes, and of any motor response to supra-orbital pressure should be confirmed. The time of death is recorded as the time at which these criteria are fulfilled.

17. Best interests

According to the Mental Capacity Act 2005 UK, the Act sets out what health care provider must consider when deciding

what is in the best interests of your patient. Health care provider should take into account: past and present wishes and feelings beliefs and values that may have influenced the decision being made, had the person had capacity other factors that the patient would be likely to consider if they had capacity (42).

Health care providers must have objective reasons for any decisions made. They must also be able to show that they have considered all the circumstances relevant to the decision in question. In trying to assess the best interests of a person lacking capacity, the health care provider should encourage the person lacking capacity to participate in the decision. To do this, it may be necessary to use specific communication methods; for example, simple language or pictures, or by using a specialist to help communicate.

- 1) Avoid discrimination: The Act specifically states that decisions cannot be based on a person's age, appearance or condition or any aspect of the person's behaviour. The appearance can refer to all aspects of a person's physical appearance, while the condition can include learning difficulties, age-related illnesses or temporary conditions (such as unconsciousness or drunkenness).
- 2) Health care provider should identify all the issues most relevant to the

person who lacks capacity and to the specific decisions to be made. These will vary from case to case, depending on the capacity of the patient and the decision needing to be made. If possible, it is advised to defer the decision until patient is likely to regain the capacity. However, in emergency situations, it may not be possible to wait for the patient to regain capacity (68).

18. Health care decision making capacity

According to the General Medical Council UK, health care provider must assess patient's capacity to make a particular decision at the time it needs to be made.

Health care providers must not assume that because a patient lacks capacity to make a decision on a particular occasion, they lack capacity to make any decisions at all, or will not be able to make similar decisions in the future.

They must take account of the advice on assessing capacity in the Codes of Practice that accompany the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000 and other relevant guidance. If assessment is that the patient's capacity is borderline, then the health care provider must be able to show that it is more likely than not that they lack capacity (69).

If the assessment leaves the health care provider in doubt about the patient's capacity to make a decision, then they should seek advice from:

- 1) nursing staff or others involved in the patient's care, or those close to the patient, who may be aware of the patient's usual ability to make decisions and their particular communication needs
- 2) colleagues with relevant specialist experience, such as psychiatrists, neurologists, or speech and language therapists. If they are still unsure about the patient's capacity to make a decision, they must seek legal advice with a view to asking a court to determine capacity.

In making decisions about the treatment and care of patients who lack capacity, they must:

- 1) make the care of the patient as their first concern
- 2) treat patients as individuals and respect their dignity
- 3) support and encourage patients to be involved, as far as they want to and are able, in decisions about their treatment and care
- 4) treat patients with respect and not discriminate against them.

They must also consider:

- 1) whether the patient's lack of capacity is temporary or permanent
- 2) which options for treatment would provide overall clinical benefit for the patient
- 3) which option, including the option not to treat, would be least restrictive of the patient's future choices
- 4) any evidence of the patient's previously expressed preferences, such as an advance statement or decision
- 5) the views of anyone the patient asks you to consult, or who has legal authority to make a decision on their behalf, or has been appointed to represent them
- 6) the views of people close to the patient on the patient's preferences, feelings, beliefs and values, and whether they consider the proposed treatment to be in the patient's best interests
- 7) what they and the rest of the healthcare team know about the patient's wishes, feelings, beliefs and values (70).

between doctor and patient is central to good decision-making (71). How much information the health care providers share with patients will vary, depending on their individual circumstances? They should tailor their approach regarding discussions with patients according to:

- 1) patient's needs, wishes and priorities
- 2) patient's level of knowledge about, and understanding of, their condition, prognosis and the treatment options
- 3) the nature of patient's condition
- 4) the complexity of the treatment, and
- 5) the nature and level of risk associated with the investigation or treatment.

Health care provider should not make assumptions about:

- 1) the information a patient might want or need
- 2) the clinical or other factors a patient might consider significant, or
- 3) a patient's level of knowledge or understanding of what is proposed.

Health care provider must give patients the information they want or need about:

- 1) the diagnosis and prognosis
- 2) any uncertainties about the diagnosis

19. Shared decision making

According to the General Medical Council UK, the exchange of information

or prognosis, including options for further investigations

- 3) options for treating or managing the condition, including the option not to treat
- 4) the purpose of any proposed investigation or treatment and what it will involve
- 5) the potential benefits, risks and burdens, and the likelihood of success, for each option; this should include information, if available, about whether the benefits or risks are affected by which organization or doctor is chosen to provide care
- 6) whether a proposed investigation or treatment is part of a research program or is an innovative treatment designed specifically for their benefit
- 7) the people who will be mainly responsible for and involved in their care, what their roles are, and to what extent students may be involved
- 8) their right to refuse to take part in teaching or research
- 9) their right to seek a second opinion
- 10) any bills they will have to pay
- 11) any conflicts of interest with the provider and provider's organization, with regards to any treatments that

the providers believe to have a greater potential benefit for the patient than those that the provider's organization can offer.

Health care provider should explore these matters with the patients, listen to their concerns, ask for and respect their views, and encourage them to ask questions.

Health care providers should check whether the patients have understood the information they have been given, and whether or not they would like more information before making a decision. They must make it clear that they can change their mind about a decision at any time. They must answer patients' questions honestly and, as far as possible practical, and fully (72).

20. Advance Directives

According to the National Hospice and Palliative Care Organization, advance care planning is making decisions about the care patients would like to receive if they become unable to speak for themselves. These are the decisions patients should make, regardless of what they choose for their future care, and the decisions are based on patient's personal values, preferences, and discussions with their loved ones. Advance care planning includes:

- 1) Getting information on the types of life-sustaining treatments that are

available.

- 2) Deciding what types of treatment, patients would or would not want should they be diagnosed with a life-limiting illness.
- 3) Sharing their personal values with their loved ones.
- 4) Completing advance directives to put into writing what types of treatment they would or would not want should they be unable to speak for themselves.

Decisions about end-of-life care are deeply personal, and are based on patient's values and beliefs. Because it is impossible to foresee every type of circumstance or illness, it is essential to think in general about what is important to them. Conversations that focus on patient's wishes and beliefs will relieve the loved ones and healthcare providers of the need to guess what they would want (73).

21. Surrogate

According to the Illinois Health Care Surrogate Act, "Surrogate decision maker" means an adult individual or individuals who

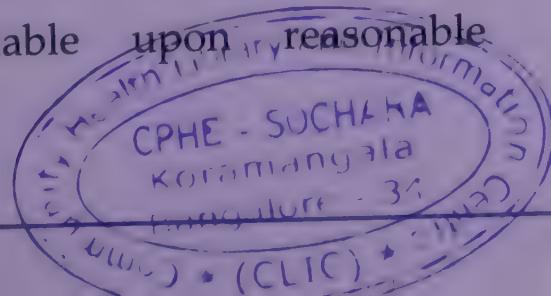
- 3) are willing to make medical treatment decisions on behalf of a patient who lacks decisional capacity, and
- 4) are identified by the attending physician in accordance with the provisions of this Act as the person or persons who are to make those decisions in accordance with the provisions of this Act (74).

The Act goes on to make the following clarifications:

- (a) When a patient lacks decisional capacity, the health care provider must make a reasonable inquiry as to the availability and authority of a health care agent under the Powers of Attorney for Health Care Law. When no health care agent is authorized and available, the health care provider must make a reasonable inquiry as to the availability of possible surrogates. A reasonable inquiry includes, but is not limited to, identifying a member of the patient's family or other health care agent by examining the patient's personal effects or medical records. The surrogate decision makers, as identified by the attending physician, are then authorized to make decisions as follows: 1) for patients who lack decisional capacity and do not have a qualifying condition, medical treatment decisions may be made according to a shared decision

1) have decisional capacity,

2) are available upon reasonable inquiry,



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making model 2) for patients who lack decisional capacity and have a qualifying condition, medical treatment decisions including whether to forgo life-sustaining treatment on behalf of the patient may be made without court order or judicial involvement. In the absence of designated or nominated surrogate decision makers, the next of kin is considered to be a surrogate. According to Organ Transplant Act of India (75) first relatives (spouse, parents, children, grandparents, brother and sisters) are considered as next of kin.

The health care provider shall have the right to rely on any of the above surrogates if the provider believes after reasonable inquiry that neither a health care agent under the Powers of Attorney for Health Care Law nor a surrogate of higher priority is available. Where there are multiple surrogate decision makers at the same priority level in the hierarchy, it shall be the responsibility of those surrogates to make reasonable efforts to reach a consensus as to their decision on behalf of the patient regarding the forgoing of life-sustaining treatment. If 2 or more surrogates who are in the same category and have equal priority indicate to the attending physician

that they disagree about the health care matter at issue, a majority of the available persons in that category (or the parent with custodial rights) shall control, unless the minority (or the parent without custodial rights) initiates guardianship proceedings in accordance with the Probate Act of 1975. No health care provider or other person is required to seek appointment of a guardian (76).

- (b) After a surrogate has been identified, the name, address, telephone number, and relationship of that person to the patient shall be recorded in the patient's medical record.
- (c) Any surrogate who becomes unavailable for any reason may be replaced by applying the provisions of Section 25 in the same manner as for the initial choice of surrogate.
- (d) In the event an individual of a higher priority to an identified surrogate becomes available and willing to be the surrogate, the individual with higher priority may be identified as the surrogate. In the event an individual in a higher, a lower, or the same priority level or a health care provider seeks to challenge the priority of or the life-sustaining treatment decision of the recognized surrogate decision maker, the challenging party may

initiate guardianship proceedings in accordance with the Probate Act of 1975.

- (e) The surrogate decision maker shall have the same right as the patient to receive medical information and medical records and to consent to disclosure.
- (f) Any surrogate shall have the authority to make decisions for the patient until removed by the patient who no longer lacks decisional capacity, appointment of a guardian of the person, or the patient's death.

22. Autonomy

According to Beauchamp and Childress; Principles of Biomedical Ethics, autonomy is respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices. This translates in practice as the right of informed consent or refusal (77,85). It is the respect for the right of a mentally competent individual to consent or to refuse clinically indicated medical treatment (including life-sustaining treatment). The choice should be based on adequate information, and the individual takes responsibility for such choice. For any medical intervention except in special circumstances, a consent form needs to be signed by the patient or

surrogate. Physicians are by common law bound to respect patient's refusal who has received complete information even if this would lead to his or her death. Respect for patient's autonomy is sometimes extended to include respect for patient's bodily integrity. For example, for mentally incompetent individuals who cannot express preferences and make choice, decisions on life-sustaining treatment should nonetheless take into account their bodily integrity (78). The physician's approach should be to address the patient as a whole person than merely as a disease entity. Open and complete disclosure of information is thus an essential part of empowering the patient in taking an autonomous decision. To be able to exercise his/her autonomy directly the patient should be mentally competent to identify and express his/her choices. If the patient has lost capacity, the right of autonomy is maintained through other means. His/her preferences are to be elicited from the next of kin or a duly appointed legal representative and are termed as "substituted judgment" (79). An Advance Will is an instrument for the expression of autonomy in anticipation of one's loss of capacity. When the patient's values and wishes are known they are integrated into the end of life decision making (80). The right to privacy judgment in India (Justice Puttaswamy vs The Union of India, 2017) adds immense weight to the Principle of

Autonomy even without an Act specific to self determination. It states that the right to privacy should be regarded as an unalienable fundamental right on its own, not as an extension of right to life. This is fundamental to restoring the right of the patient to choose the manner of his treatment when facing terminal illness. The right to privacy would be violated if this principle is not followed in practice. This right must be seen to be respected even when the patient is incompetent, and would operate through a mechanism: either an instructive directive such as Advance Will or an authorized power of attorney appointed by the patient; in the absence of these the natural surrogates such as the next of kin. The Mental Healthcare Act 2017 further supports the Principle of autonomy pertaining to healthcare and the right to use an instrument such as Advance Will.

23. Beneficence

According to Beauchamp and Childress; Principles of Biomedical Ethics, this considers the balancing of benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient. It also includes duty of care and due regard for patient's welfare and interests (to preserve life, relieve suffering, limit disability). Related professional terms and concepts include patient's best interests and patient's benefit (78,85). Beneficence flows from

the fiduciary obligation to act always in patient's best interests. In terminal illness since benefits of a curative intervention are negligible, foregoing of life support would be in patient's best interests (77). This is even more so when patients' values and preferences suggest that such interventions are unwanted. Best interests also include protecting him/her and the family from economic or social difficulties when these are clearly expressed (81). Physician's insisting on continuation of futile therapies is therefore to be regarded as violation of this principle.

24. Non-maleficence

According to Beauchamp and Childress; Principles of Biomedical Ethics, it involves avoiding the causation of harm; the healthcare professional should not harm the patient. All treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of treatment. In the context of end of life care, to avoid prolonging suffering by employing potentially inappropriate medical interventions, and to adequately consider the risks and harms of interventions (78). Harm confined only to the physiological stand point would be too narrow an interpretation. A dying patient and family should be given the opportunity to prepare for death (80).

An appropriate environment for ensuring good death should be made available. All

the while whole person interests should be safeguarded. The family too must be protected from harm that may accrue from incomplete information, financial pressure of disproportionate treatments and posttraumatic stress disorder from inadequate attention to counseling during the dying process and bereavement.

Freedom from pain and distress is a fundamental right and withholding adequate palliative therapy would violate this principle. The doctrine of "double effect" addresses the situation when adequate analgesia and sedation may have the unintended side effect of shortening the dying process (82). This principle clearly sets the obligation to provide freedom from pain and distress above the principle to do no harm provided the harm is unintended (83). Intention is revealed in the care taken to titrate the drug dosing which would mean that protocols for palliative therapy should be in place and documentation should be meticulous (84). However, doses beyond usual recommendations should be adequately justified.

25. Justice

According to Beauchamp and Childress; Principles of Biomedical Ethics, it

involves distributing benefits, risks and costs fairly; the notion that patients in similar positions should be treated in a similar manner. Treating all persons according to what is fair or due to them. A related concept often considered is equity. An individual should not be unfairly treated (discriminated) based on disability, age, social status, etc. On the other hand, an individual cannot claim unlimited right (e.g. to be treated at all costs), without regard to the impact on other persons or to scarcity of resources (78,85). In other words, social justice means allocating resources appropriate to the medical condition of the patient in order to maximize their benefits and minimize wastage. Futile application of therapies would clearly violate this social obligation. Situations may arise when patient or family may insist on therapies physicians would consider inappropriate, when the principles of autonomy and justice may appear to be in conflict. In such an event repeated communication and negotiating a middle path may be the best course. It would also be worth remembering that the physician is bound to act only according to professional standards of care and not obliged to follow blindly the dictates of the patient (83).

CONCLUSIONS AND FUTURE DIRECTIONS

The consensus document under the aegis of the Indian Council of Medical Research (ICMR) has brought up-to-date, a glossary of terms relating to end of life care, limitation of life sustaining treatment and Palliative Care. The definitions are based on accepted global standards in contemporary bioethical, medical and legal literature. Currently in India, the usage of the terms across professional, legal and social domains has lacked standardization and clarity. This has proved to be a significant barrier to building consensus for public policy relating to End of life Care, Withdrawal and Withholding of medical interventions, Right to Advance Will, and Euthanasia. This anomaly is expected to be corrected with this comprehensive position statement on the terms. This document is prepared to serve as an authoritative reference for dialogue, research and publications and to inform the ongoing formulation of a medico-legal framework for these areas.

BENEFITS ACCRUED

- The multi professional consensus definitions lend themselves well to be understood by stakeholders across the several disciplines concerned with End of life and Palliative care.
- It brings clarity to outdated, inconsistent and ambiguous terms used in End of Life and Palliative Care in India.
- It will serve to generate awareness of contemporary ethical and legal dimensions in medical care among both professionals and lay public.
- Based on standard methodology, it is an authoritative resource to inform legal opinion and public policy.
- Indian physicians seeking to practice as per international ethical guidelines will be better understood and protected as the definitions are rooted in contemporary bioethical concepts and principles.
- Indian patients will be benefited by the universally accepted ethical principles finding expression in Indian medical practice.

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